

First Year of AIDS Services Delivery Under Title I of the Ryan White CARE Act

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Synopsis

This is a review of (a) the emergency assistance for ambulatory HIV medical and support services

provided in the first year by eligible metropolitan areas (EMAs) funded under Title I of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990, (b) the varied responses and processes by which the 16 urban areas receiving Title I funds in 1991 met legislative mandates, (c) the central nature of planning councils under Title I and their formation and functioning, and (d) issues related to current implementation and future expansion of Title I to additional eligible metropolitan areas.

Integral to the review is a brief discussion of the history of AIDS and HIV infection, particularly in cities receiving CARE Act funding, an overview of Title I requirements, and a description of the organizational structures cities are using to implement Title I.

Information on Title I EMAs is based on analysis of their 1991 applications, bylaws of their HIV service planning councils, intergovernmental agreements between Title I cities and other political entities, and contracts executed by Title I grantees with providers for the delivery of services. Interviews with personnel in several Title I EMAs, including planning council members and grantee staff members, provided additional information.

This is the first descriptive accounting of activities related to the 1991 applications for and uses of Title I funds, and the administrative and service issues related to this process.

THE EPIDEMIC SPREAD of acquired immunodeficiency syndrome (AIDS) indelibly marked public health in the United States in the 1980s. From the first reported cases of AIDS in June 1981 (1) through identification of the human immunodeficiency virus (HIV) as the causative agent in 1984, the nation dedicated substantial biomedical and pharmaceutical research resources to clinical trials, public education and information on prevention and, from 1987 on, demonstrations of coordinated

patient-centered care and federally funded prevention and care programs.

At the end of the first decade of the HIV epidemic, the Congress authorized funding of outpatient and ambulatory medical and support services for the increasing numbers of people with AIDS and HIV infection. That legislation, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act (2), was signed into law August 18, 1990.

Services in those urban areas with the highest number of reported AIDS cases were authorized under Title I of the act, formula grants to all States under Title II, and early intervention services under Title III. Title IV authorizes general activities, including pediatric research initiatives. Funds were allocated in 1991 and 1992 for all titles except IV and a portion of III.

In fiscal year 1991, the first year for which funds were available, \$86 million was allocated under Title I to metropolitan areas that, by June 30, 1990, had reported to the Centers for Disease Control (CDC) more than 2,000 cumulative cases or had a per capita incidence of cumulative AIDS cases not less than .0025 (3). Cities qualifying were defined as eligible metropolitan areas (EMAs). As of the qualifying date, 85.8 percent of the people diagnosed with AIDS lived in an urban area with more than 500,000 population (4). Furthermore, 59 percent of the cumulative AIDS cases (82,304 of the 139,765 cases) had been reported by 16 urban areas that subsequently applied for and received Title I funds as EMAs.

When the first Title I funds were awarded, the growing number of people diagnosed with AIDS in these EMAs had placed heavy demands on urban medical and social support systems. Because of the nature of the epidemic, however, the populations most heavily impacted varied among the EMAs, and this in turn led to substantial variations in patterns of needed care and services. For example, according to data reported in EMA applications and confirmed by CDC in its public information data set for June 1990, the proportion of reported cases among women ranged from 1.6 percent in San Francisco, CA, to 26.2 percent in Newark, NJ. The proportion of cases in persons less than 13 years of age (1.7 percent nationally) ranged from 0.4 percent in Dallas, TX, to 3.5 percent in San Juan, PR, and 3.9 percent in Miami, FL (5).

From 1981 to the present, more cases have been reported nationally among whites than among other racial and ethnic groups. Examination of cumulative incidence rates, relative risks, and seroprevalence data, however, shows that minority populations in many of the EMAs are disproportionately affected by the epidemic, although again there are variations. Reported AIDS cases among African Americans in the EMAs ranged from 7.8 percent in San Diego, CA, to 73 percent in Newark; the proportion of cases among Latinos ranged from 1.8 percent in Atlanta, GA, to 28.4 percent in Miami to 98 percent in San Juan (5). More than 20 reported cases among Asian-Pacific

Islanders occurred in only five EMAs: Chicago, IL, Los Angeles, CA, New York, NY, San Diego, and San Francisco. The first four of these cities were the only EMAs to report more than five cases among native American Indians. Additional diversity exists among the EMAs in the sexual orientation of persons seeking HIV-related care and in the proportion of injection drug users who need care. For example, the AIDS cases reported among heterosexual users of injection drugs ranged from 3 percent in San Francisco to 59 percent in Newark (5).

This concentration of reported AIDS cases in urban areas, combined with the diversity of affected populations, led to the inclusion of the emergency funding provisions of the CARE Act contained in Title I.

Title I Requirements

Within the CARE Act, Title I reflects congressional recognition of the variations among municipal health care systems as well as differences in the epidemiology of the HIV epidemic from one urban area to another. The legislation requires that emergency grant assistance support a continuum of outpatient and ambulatory health and support services and inpatient case management services that prevent unnecessary hospitalization of people with HIV infection or allow them to be discharged more quickly from hospitals. The services specifically include case management and comprehensive treatment. The Health Resources and Services Administration (HRSA) of the Public Health Service is the designated funding agency.

Planning councils. Priorities for these services must be established by HIV Health Services Planning Councils in each EMA whose membership represents 11 categories specified in the CARE Act. The act requires that persons with AIDS and HIV infection be voting members on the planning councils because they are central to the planning and priority setting process. Other members must represent health care providers, community-based service providers, social service agencies, local public health departments, State government, nonelected community leaders, mental health providers, hospital or health care planning agencies, previous demonstration projects funded by HRSA, and recipients of CARE Act Title III funds.

Planning council size is determined by the EMA's chief elected official (CEO) who is also delegated responsibility for appointing council members. Additionally, planning councils develop

plans for the organization and delivery of HIV-related services and assess the efficiency of the administrative system for allocating funds to groups and metropolitan areas where the greatest need exists. Although the CEO is responsible to HRSA for administering Title I, this official must allocate funds according to the priorities established by the planning council.

Title I also directs that funding under the act not replace existing HIV service funds and that it reach those persons most in need of HIV-related services. Specific provisions are as follows (6):

- Political subdivisions within the EMA must maintain their pre-existing level of funding for HIV-related care and not use CARE Act funds to maintain such levels of expenditures.
- Grant recipients must participate in an established HIV community-based continuum of care, if it exists.
- Grant funds will not support services that are reimbursable under any other program.
- HIV health care and support services provided by this grant assistance will be made without regard to the ability of a person to pay, or to the person's past or present health condition, and in a setting accessible to low-income people with HIV disease.
- An outreach program will inform low-income people with HIV disease that such services are available.

Half of the appropriated funds are awarded by formula (based on cumulative AIDS cases and cumulative AIDS case incidence), and half are awarded competitively among the EMAs, based on their supplemental applications (7) that must include a plan for spending additional funds based on needs not met by the formula grants, a high incidence of AIDS, and proof of the existing commitment of area resources. The needs of infants, children, women, and families also are to be addressed, and estimates about the average cost of providing HIV services to all patients and populations are to be provided to HRSA (8).

The CEO of the city or county with the largest number of reported AIDS cases that provides HIV health care services within an EMA is designated to receive both formula and supplemental funds. If an EMA includes other political subdivisions that account for at least 10 percent of the area's reported AIDS cases, an intergovernmental agreement on allocation of Title I funds and services must be negotiated and signed by CEOs of the involved political subdivisions.

These Title I requirements build on the Robert Wood Johnson Foundation's \$17 million competitive grant program for the organization and provision of HIV-related care in 11 metropolitan areas (9), and on HRSA's 25 HIV adult service demonstration programs supported by \$68.2 million in grants from 1986 to 1990 (10). Although the requirements provide a structure for planning and allocating funds for HIV-related services, they also allow for local responses based on the nature of the epidemic and the existing service delivery system.

Responses of the EMAs

Half of the 16 urban areas qualifying for 1991 Title I funds are counties; half are cities (table 1). Mayors are the CEOs receiving Title I funds for the cities; the county judge or the chair of the board of supervisors or of the county commissioners receives Title I funds for the counties. Seven of the eight counties—Fulton County, GA, Dallas and Harris Counties, TX, Broward and Dade Counties, FL, and San Diego and Los Angeles Counties, CA—are in the southern or southwestern regions of the country. Seven of the eight cities—Boston, Chicago, New York, Newark, Philadelphia, San Francisco, and Washington, DC—are in the northern, midwestern, or western regions of the country. The eighth city is San Juan, Puerto Rico; the eighth county, Hudson, is in New Jersey.

Because these funds are provided for emergency relief, the Congress mandated a rapid application, review, and allocation process. From the date that the appropriations bill was signed (November 5, 1990), the EMAs had 45 days to submit formula grant applications (they could request a 30-day extension from HRSA) and 102 days to submit supplemental grant applications. Operating under a December 20, 1990, application deadline, EMAs had a series of tasks to accomplish to meet application requirements. These included determining which political subdivision would administer the funds, identifying needed intergovernmental agreements, forming the HIV services planning council, establishing service priorities that often involved holding public hearings and planning meetings, and developing and reviewing numerous planning documents.

To meet the deadlines, many EMAs initiated actions before the appropriations bill was signed. By September 7, 1990, the City of San Francisco Department of Public Health had developed recommendations for the formation of the HIV health services planning council and a list of potential

Table 1. Eligible Metropolitan Areas (EMAs) qualifying for Title I funds under the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, 1991

EMA, grantee	Number of AIDS cases ¹	CARE award (\$1,000s) ²	Administering agency	Planning council members ³
Atlanta, Fulton County, GA ⁴	2,217	\$ 2,124	County manager	13
Boston, Boston, MA ⁴	2,326	2,236	City health department	45
Chicago, Chicago, IL	3,471	3,230	City health department	33
Dallas, Dallas County, TX	2,360	1,379	AIDS Arms Network	25
Ft. Lauderdale, Broward County, FL	2,217	1,807	County health department	30
Houston, Harris County, TX ⁴	4,137	3,710	Greater Houston AIDS Alliance	66
Jersey City, Hudson County, NJ ⁴	1,537	1,563	County health department	40
Los Angeles, LA County, CA	9,199	7,848	County health department	50
Miami, Metro Dade County, FL ⁴	3,686	3,044	County manager	22
New York, New York City, NY	26,775	33,457	City health department	42
Newark, Newark, NJ	3,885	4,112	City health department	24
Philadelphia, Philadelphia, PA ⁴	2,960	2,324	City health department	50
San Diego, San Diego County, CA	2,084	1,460	County health department	19
San Francisco, San Francisco, CA	8,457	12,714	City health department	28
San Juan, San Juan, PR	2,509	1,681	City health department	25
Washington, DC, Washington, DC	3,895	3,393	City health department	40
Totals	81,715	\$86,083		552

¹ As of June 30, 1990. ² Rounded to \$1,000. ³ As of June 1991. ⁴ Expanded from existing HIV-AIDS planning bodies.

council members that would meet the criteria of Title I. The San Diego planning council had been established by November 6, 1990. A week after the appropriations bill had been signed, the Boston AIDS Consortium had developed a draft proposal addressing formation of the planning council, the public testimony process, and development of funding mechanisms and priorities.

Determination of the political subdivision to administer the funds. In 14 EMAs, the CARE Act's definition of the administrator of funds clearly referred to one entity. In two areas, Chicago and Jersey City, either the city or the county could have been the Title I administrator under the act's definition. In both these sites, the city and county mutually determined who would administer the funds and spelled this out in intergovernmental agreements. The City of Chicago and Cook County agreed that the city would administer the CARE Act funds; Jersey City and Hudson County agreed that Hudson County would administer the funds.

Agencies designated by the 16 EMAs to administer Title I funds fell into three types: departments of health, county managers, and nonprofit agencies (table 1). The majority of CEOs delegated their authority to administer Title I funds to the departments of health under their jurisdiction. In Philadelphia and New York, the departments of health in turn contracted with a private agency to manage the Title I funds. In Dallas and Harris Counties, TX, the CEOs initially delegated their authority directly to nonprofit HIV service agencies.

Establishment of intergovernmental agreements. Four EMAs—Atlanta, Chicago, Jersey City, and Washington, DC—include at least one county that reported 10 percent or more of the area's AIDS cases and provides HIV-related services. Consequently, to comply with the CARE Act, they established intergovernmental agreements with adjoining political subdivisions. In addition, Fort Lauderdale, Miami, New York, Newark, and San Juan, on their own initiative, developed intergovernmental agreements with their States and, in some cases, with other political entities.

Intergovernmental agreements establish the role of the political subdivisions in relation to planning council membership and priorities, the mechanisms for administering funds among subdivisions, and may include mechanisms for technical assistance and cooperation among the political entities of the EMA. In Chicago and Washington, DC, for example, the agreements specify that funding allocations will be made in accordance with the local demographic characteristics of the HIV epidemic.

The Chicago agreement details the planning process used to identify and prioritize needed HIV services. The planning process started with the AIDS Strategic Plan developed by the city's department of health. Based on public participation, this plan was updated with information from each of the three counties of the EMA and continues to serve as the basis for service assessments (11). The DC agreement also identifies gaps in services for HIV-related care in northern Virginia, and consequently attaches priority to meeting those needs

through Title I funding. These gaps in HIV services include few private practitioners taking Medicaid or indigent patients, an inadequate volume of dental services, and insufficient case management services (12).

New York and San Francisco voluntarily allocated funds to political subdivisions within their respective EMAs that had reported less than the required level of AIDS cases necessary for such shared funding. An agreement between the State of Florida and Broward County ensures that the State shall provide access to all records, data, and expertise that would assist the county in planning, implementing, and administering the CARE Act (13).

Establishment of councils. At least six EMAs designated planning councils by expanding existing HIV-AIDS planning bodies, including HRSA-funded AIDS Service Demonstration Projects (table 1). The remaining planning councils are new entities although they include members previously involved in community HIV-related activities. Most of the planning councils have more than one representative from each of the required 11 membership categories. The number of planning council members varied in the 1991 applications from 13 in Atlanta to 66 in Houston. The number of planning council members identifying themselves as HIV positive ranged from two in Chicago to six in San Francisco. Examples of the types of organizations represented on planning councils, in addition to those mandated by the legislation, are housing organizations, drug treatment providers, local chapters of the American National Red Cross, United Way, the Department of Veterans Affairs, private foundations, and city councils.

Close examination of the structure and initial functioning of the planning councils reveals both common themes and tremendous variation. All planning councils demonstrate some sharing of decision making between council members and the CEO. In those that expanded a pre-existing planning body to become the Title I council, the process of appointing additional members to achieve legislatively required and community desired representation was frequently shared. For example, in Philadelphia, the mayor expanded the Philadelphia AIDS Consortium by appointing 6 new members; the consortium appointed 15. In Boston, the CEO established the Steering Committee of the existing Boston AIDS Consortium as the Title I HIV services planning council. Additional members were recommended by the steering com-

Table 2. Dollars (in thousands) and percentage of the total for service programs under Title I of the Ryan White Comprehensive AIDS Resources Emergency Act

Service	Dollars	Percent
Primary care	\$24,785	34.6
Case management	9,609	13.4
Medications	8,958	12.5
Support services ¹	6,876	9.6
Housing related	5,650	7.9
Mental health	5,271	7.4
Home health care	2,425	3.4
Substance abuse	1,827	2.5
Outreach case finding	1,755	2.4
LTC ²	1,324	1.8
Other ³	3,865	4.5
Total⁴	\$71,686	100.0

¹ Transportation, meals, volunteers, peer support.

² Includes adult day care and hospice, rehabilitative, and institutional care.

³ Includes evaluation, systems development, interpreter services, alternative therapies, public hearing regional planning, respite, pediatric day care, technical assistance, planning council support, HRSA Demonstration Projects.

⁴ Excludes administrative unallocated funds.

SOURCE: Information received by HRSA as of 12/31/91.

mittee (with input from the city), considered by a nominations committee, then selected by full vote of the steering committee, and officially appointed by the mayor.

In the remaining EMAs that created new councils, the CEO appointed members, although again appointments were often based on recommendations advanced by community groups active in HIV-AIDS. In San Francisco, for example, the AIDS Health Services and People of Color Advisory Committees developed a list of persons recommended for membership, based on requirements of the CARE Act while at the same time balanced among three representative categories—community based organizations that provided care to people infected with HIV, hospitals and institutions, including the San Francisco Department of Public Health, and the community at large, including persons with HIV infection. Among all planning councils, terms of office range from 1 to 3 years, except in New York City and Los Angeles where planning council members serve at the pleasure of the mayor.

The chairperson, who in almost all EMAs presides over meetings and appoints the chairs and members of committees, is appointed by the CEO in eight cities, and is elected by the council members in eight. The majority of planning councils have standing committees that include additional nonvoting community representatives. In some EMAs, the committees are related to council functions such as the bylaws, nominating, finance, and executive committees in New York City. In

Table 3. Fiscal year 1991 service priorities and total funds (in thousands) awarded under Title I of the Ryan

EMA	Primary care	Case management	Medications	Support services ¹	Housing related	Mental health	Home Health care	Substance abuse
Atlanta	X	X		X			X	
Boston	X	X		X	X	X	X	
Chicago	X	X		X	X	X	X	X
Dallas	X	X		X	X	X	X	X
District of Columbia	X	X	X	X		X	X	
Fort Lauderdale	X	X	X		X			
Houston	X	X		X		X	X	X
Jersey City	X	X		X		X	X	
Los Angeles	X	X		X	X	X		X
Miami	X	X		X	X	X	X	
New York City	X	X	X	X	X	X	X	X
Newark	X	X		X				
Philadelphia	X	X		X		X	X	X
San Diego	X	X		X		X	X	
San Francisco	X	X	X	X	X	X	X	X
San Juan	X	X	X	X				

¹ Transportation, meals, volunteers, peer support.

² Includes adult day care, hospice, rehabilitative, and institutional care.

³ Includes evaluation, systems development, interpreter services, alternative

therapies, public hearing regional planning, respite, pediatric day care, technical assistance, planning council support, HRSA Demonstration Projects.

⁴ Excludes administrative unallocated funds.

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others, the committees are related to services. As an example, Jersey City's 11 committees correspond to HIV services for mandated membership categories. One of Houston's subcommittees addresses targeted populations (children, women, and families) for HIV services. In most cities, the committees are responsible for a mix of functional and programmatic tasks.

By the time EMAs applied for Title I funds, most of the planning councils had developed by-laws that, at a minimum, governed conduct of meetings. Some of the more innovative aspects of planning council requirements are

- In Atlanta, each member must attend continuing orientation-education sessions on aspects of HIV care.
- In Chicago, the mayor and the county executive share the power to appoint members and officers and to approve funding allocations.
- In Los Angeles, New York City, and San Juan, provisions for nonvoting participants are established.

Service Priorities

As can be expected, the nature of the epidemic within the various EMAs gives rise to a wide range of variability in the awarded contracts. The size of the contracts varies greatly from \$2,000 for a health center in Boston to furnish transportation for HIV-AIDS patients to \$1,130,178 for the Human Resources Administration in New York City for apartments for HIV patients. The number of service providers within the EMAs receiving Title I funds also varies widely, from 7 in Atlanta to more than 100 in New York City.

In the first year of funding, EMAs allocated their Title I resources according to six top priorities: primary care (34.6 percent), case management (13.4 percent), medications (12.5 percent), support services (9.6 percent), housing-related services (7.4 percent), and mental health services (7.3 percent). Other priorities ranged from 1.8 to 3.4 percent of total funds (table 2).

Primary care and case management received Title I funds in all EMAs (table 3). Primary care includes early intervention, comprehensive ambulatory medical care, gynecological care, and dental care. The percentage of funds devoted to primary care among cities varied greatly, from 78 percent in Atlanta to 10 percent in Boston. Funds allocated to case management also varied, from 33 percent in Newark to 3 percent in Jersey City. The third priority, medications, was funded by five EMAs. New York City's allocation accounts for 77 percent of the total EMA funding for medications.

White Comprehensive AIDS Resources Emergency Act

Outreach case funding	LTC ²	Other ³	Total ⁴
			\$ 2,033
X		X	2,113
X		X	3,012
	X		993
X	X	X	2,903
		X	1,717
		X	3,525
X	X	X	1,455
X	X	X	7,785
		X	2,927
X		X	22,571
			3,505
X			2,274
X			1,379
	X	X	11,696
			1,597

SOURCE: Information received by HRSA as of 12/31/91. Information on New York and San Juan represents planned, rather than appropriated commitments.

Support services include transportation, food, volunteer services, peer support, and other activities that improve the living situations of persons with HIV infection. In all, 14 EMAs elected to fund support services. Grant funds for services within EMAs varies widely, from 34 percent in Dallas to 2 percent in Atlanta. Eight EMAs allocated funds to housing-related services, making it the fifth overall priority. These services were deemed essential since the housing sites thus assisted are often the only places where other Title I services can be delivered to once homeless or displaced HIV patients. This category includes services that promote the ability of patients to locate suitable housing in the community such as housing coordinators, services in apartments, and emergency housing subsidies.

Discussion

At the conclusion of the first year of implementation, Title I grantees had identified many implementation issues. Some have been resolved; others will have to be addressed in future program years.

Although the act requires coordinated HIV-related services in EMAs, it does not define how and to what extent coordination should occur. Coordination is challenged by the nature of HIV disease. It is a chronic condition with episodes of acute illness interspersed with periods in which normal activities of daily living may be resumed. Coordination in each EMA also is influenced by the mode of transmission of the virus and the

development of the epidemic, and consequently by the populations most likely to become HIV positive and require care. These groups include homosexual males who often face cultural and legal censure, substance abusers who are by their actions violating the law, and ethnic and racial populations who often have difficulty accessing systems of medical care and support services. Through Title I, representatives of these groups must now be included in the planning and delivery of HIV-related care.

Council formation. Including representatives from these diverse groups, as well as health care providers, on the planning council and in the priority development process has been labor intensive and time consuming. Maintaining such representation is an ongoing process. To encourage this inclusive participation, initial methods involved developing council committees that often included nonvoting members from a variety of community constituencies or providers, expanding council size, adding non-voting council and committee members, encouraging and responding to advocacy by affected populations, and holding public hearings. In addition, all EMAs have adopted bylaws to avoid conflicts of interest and to ensure member participation.

Priority development. Agencies that may not have worked together in the past, such as health departments, large medical institutions, and community-based organizations, must overcome competition for funds and jointly prioritize HIV-related service needs. Working together through the mechanisms of the planning councils, and without congressional or HRSA oversight, these agencies participated in a variety of approaches to develop local priorities. These ranged from externally focused processes, such as public hearings held in cities like Boston and Los Angeles, to internal processes. Houston is an example of internal processes. There, four council task groups (ambulatory care, case management, psychosocial, and pediatric-women-and-families) established priorities that were negotiated in full council meetings. Some EMAs combined these processes. San Diego, for example, held community forums to identify priorities, then, within service categories, brought community organizations and members together to come to agreement on specific priorities.

How the EMAs are to coordinate Title I activities with other HIV-related service programs, including those funded by States under Title II, is ill-defined in the CARE Act. This may affect the

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funding of services. The issue was specifically raised at a HRSA-sponsored meeting of all Title I EMAs July 1-2, 1991, in Chicago. In areas such as Florida, where both an EMA planning council and Title II consortia exist, some HIV service providers receiving Title I funds contended that the State ignored them when Title II funds were disbursed. In other EMAs, notably San Francisco, Philadelphia, and Dallas, coordination concerns are met through shared members who sit on both the Title I planning council and the Title II consortia.

Technical assistance. To determine whether Title I services are meeting the needs of priority populations, as defined by the respective planning councils, requires some form of monitoring and reporting. Many EMAs have requested technical assistance to develop automated patient and resource monitoring systems. Several EMAs, such as those of Washington, DC, and Los Angeles, began developing automated data collection and reporting systems early in the first year of funding, building on previous systems. Ultimately, data collected through this process will help HIV service providers improve their services and help planning councils project the medical and social service needs of diverse populations. Currently, there are no Federal requirements for documenting the clients served by Title I- and Title II-funded service providers although the CARE Act does stipulate that applications for supplemental funding include demographic and cost information (14).

To assist grantees and providers in obtaining information essential for planning and documenting the impact of CARE Act funds, HRSA has worked with people with AIDS, providers, grantees, and national organizations to draft a model uniform reporting system (15). This proposed system is structured to protect completely the identity of individual patients who will remain anonymous. System software and technical assistance will be

available initially on a pilot basis through supplemental awards to grantees and providers to give them access to data such as the ethnicity, insurance status, demographic characteristics, and immunological and medical information about clients and characteristics of the services received. Without this or similar reporting systems, there will be no documentation of the numbers and diversity of clients served or of the types and quantity of services available to people with HIV. Lack of reporting systems will also make it impossible for HRSA or its grantees, including care providers, the planning councils, or the Title II consortia, to determine whether planning council priorities were met.

Funding. Another important issue is future funding for HIV-related care, through Medicaid-Medicare, Title I, and State and local sources. Costs of care are rising because of increasing demand for HIV-related services by persons who may not have health insurance coverage but who have immune deficiency, are living longer, and require additional care with increasingly expensive pharmaceuticals. The proportion of these costs paid by Federal, State, or local government, employers, and patients and families is different in all States and changes over time, depending on factors such as employment, Medicaid eligibility, and health care reform.

In a recent forecast, HIV-related medical costs are projected to increase 21 percent each year between 1991 and 1994 (16). The current estimate of annual costs of AIDS care per patient is \$38,000, and lifetime costs are estimated to exceed \$100,000 (17). A large portion of these costs include outpatient care, mental health counseling, pharmaceuticals, and laboratory tests—the services targeted by the CARE Act. Part of this rise in medical costs is also due to a predicted 40-percent increase by 1995 in the number of people with HIV infection who will require medical and support services (18).

Additional metropolitan areas will become eligible for Title I funds as the epidemic increases and as CDC broadens its definition of AIDS. Two additional metropolitan areas, Baltimore, MD, and Oakland, CA, reported more than 2,000 cases to CDC by March 31, 1991, thus qualifying for fiscal year 1992 funding. Even without an expanded AIDS case definition, six additional areas reported at least 2,000 cases by March 31, 1992, thus becoming eligible for fiscal year 1993 Title I funds. An unknown number will qualify in 1994.

As the demand for HIV-related services increases and more cities become eligible, stable Title I

funding may result in limiting support to the most critical patient needs, primary care and medications, to the detriment of support services. Health care insurance reform could also affect the need for Title I funds that, by law, cannot be used to enhance any third party reimbursements, whether or not such payments cover the cost of services provided.

Future models. Title I of the CARE Act is one approach to encouraging communities to plan, prioritize, and coordinate services with participation by the populations receiving services. For Title I, planning councils are the central feature of the process. Despite long hours of discussion required to achieve consensus, disagreement in some EMAs over selection of members who represent the community, competing service priorities, and the process by which funds are awarded to the service providers best able to care for diverse populations, it is our judgment that communities have been well served by planning councils. With their guidance, these EMAs are moving forward to respond to changing needs of people with HIV. Participation of persons with HIV infection and AIDS has been essential to the success of this process, and we believe that this model, based on including users of services in planning and prioritizing use of service dollars, should become standard practice for similar initiatives in the future. In the first year of operation, the act's requirements have resulted in a variety of individualized responses to the epidemiology of the local epidemic, local pre-existing services infrastructure, and special care needs of different populations of people with HIV infection.

In its orientation to community based planning coalitions, Title I is part of a broader series of public health initiatives such as Healthy Start and ASSIST (The American Stop Smoking Intervention Study). These initiatives are based on the belief that residents of local communities, including providers and persons in need of services, need to examine how they are spending limited resources. Consequently, knowledge and experience gained during implementation of Title I can influence future approaches to organizing and funding health and support care in local communities.

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